Chapter 6

The Process of Adherence to Treatment in People Living with HIV

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Abstract

The purpose of this chapter is to review the concept of adherence and analyze its implications for the social construction of the patient as a subject, since this affects the relationship established with the health services for the maintenance of care. The facilitators and barriers to adherence reported in the literature are presented, based on studies focused on the perspective of people living with HIV. At the end of the chapter, the individual elements that promote adherence to treatment are shown, according to the experience of highly adherent patients. In addition, individual and contextual barriers to the adherence process are identified in the pharmacological and nonpharmacological dimensions.

Keywords: adherence, medical treatment, lifestyle, facilitators, barriers

1. Introduction

The development of highly active antiretroviral treatment (HAART) has allowed HIV infection to become a chronic condition. This historic event has transformed the experience of people living with HIV, since it has allowed them to extend their survival time and increase their quality of life [1]. However, this biomedical breakthrough has generated important challenges for public health. One of them is universal access to treatment. Social inequality in terms of the intersection between gender, social class, ethnic group, sexual orientation, or geographical region places patients at different levels of vulnerability regarding access to treatment. Likewise, social inequality affects the continuity of long-term treatment, as patients differ

in access to services that allow maintaining care over time as food, education, health, housing, employment, and transportation, among others. For this reason, public health cannot be limited to a "pharmaceuticalization" or exclusive emphasis on access to medication, but it requires considering the social and economic conditions that affect the possibilities of patients to maintain a long-term pharmacological treatment [2].

The second challenge, which is addressed in this chapter, is the promotion of adherence to treatment in people living with HIV. This challenge is linked to the facilitation of psychosocial processes that allow long-term adherence, while the previous challenge focuses mainly on the structural conditions associated with adherence. Unlike pharmacological treatment for other medical conditions, HAART requires an efficacy greater than 95% to control the number of copies of the virus in the body. The suboptimal medication intake is associated with higher levels of morbidity and mortality as well as the emergence of drug-resistant viral strains. This reduces the effectiveness of subsequent treatment schemes [3].

The lack of adherence to treatment has multiple consequences for the state: increased expenses for hospitalization, care for opportunistic infections, and changes in treatment schemes and laboratory studies. In turn, lack of adherence increases the risk of HIV transmission in populations and the development of new strains resistant to treatment [4].

The study of adherence to treatment in people living with HIV has focused mainly on pharmacological adherence. It is necessary to develop a comprehensive perspective on adherence, which not only includes medication intake but also the adoption of a healthy lifestyle in multiple areas. The following section analyzes the concept of adherence and its influence on the patient's relationship with health services.

2. Perspectives on adherence

The social construction of adherence influences the way in which patients are constituted as subjects, the type of relationships they establish with health personnel, and the policies of health services for patient care. Previously the term "compliance" was used to refer to the degree to which the patient followed medical recommendations for taking the medication or making lifestyle changes. The concept was criticized because it assumed a hierarchical relationship between the doctor and the patient, considered that the medical recommendations were correct and that the failure in the treatment was mainly the responsibility of the patient for not complying with the recommendations [5].

In contrast, the concept of adherence emerged in a historical moment where patients had greater access to information technologies, which expanded the possibilities of having information about their diagnosis and treatment. This allowed patients to develop a sense of agency, establish a dialog with health personnel and adopt a critical stance during the treatment process. Likewise, the emergence of chronic conditions sets limits to the power of health personnel and forced the incorporation of the patient in the planning and maintenance of long-term care.

Adherence means a different type of relationship to "compliance": a horizontal, democratic, and collaborative relationship for the maintenance of care over time. The concept not only implies a change in the relationship with health personnel; it also represents a change in the subject: the patient becomes an active agent in the treatment process. Health services not only attribute responsibility to the patient for taking the medication or following the health recommendations; they also encourage the patient to request information about their health status and to participate in decision-making during treatment. It should be noted that this notion of the patient is based on two assumptions: care depends on the patient's will, and the patient is interested in maintaining or improving their health status.

From biomedical discourse, it is assumed that subjects are able to choose; act rationally, intentionally, and responsibly; and make decisions in terms of costs and benefits. However, the possibility of deciding is determined structurally. This means that the subjects are not completely free to decide; they can select the possibilities available for their local context, according to their socioeconomic position and the dominant cultural values [6]. As previously mentioned, social inequality not only affects access to treatment; it also limits access to services that favor the maintenance of care and the patient's ability to become adherent.

In the particular case of HIV infection, there are two additional elements that affect the development of adherence. The social processes of stigma and discrimination [7] contribute to the exclusion of patients from health services, the delay in diagnosis, the rejection of the medical condition and treatment, the concealment of the diagnosis, and the reduction of social support. Close connection with these processes is the emotional discomfort, because the suffering caused by knowing the serological status can manifest itself in rejection toward diagnosis and health services; the development of risk practices or the appearance of a psychological disorder that limits the capacity for health care [8].

While it is important to consider that adherence requires an active agent in their self-care that maintains a collaborative relationship with health services, it is also assumed that the patient's agency is limited. There are different possibilities for patients to become adherents, due to structural inequalities, the processes of stigma and discrimination, and the emotional distress generated by the HIV diagnosis. Therefore, adherence is not a state that is achieved by all patients at the same time.

It is more appropriate to consider adherence as a dynamic process that develops over time [9], influenced by the social, economic, and cultural context surrounding the patient. Adherence is also affected by the learning process that arises from the patient's personal experience with diagnosis and treatment. This means that people living with HIV have different temporalities and rhythms to become adherent patients. Adherence is not a state that is reached once and for all, but a process that must be continually updated. At any point in treatment, the patient can become nonadherent, either intentionally or involuntarily [10].

From an integral perspective of patient care, it is assumed that there are two complementary dimensions of adherence. The first dimension is pharmacological adherence, which involves taking the medication and following the instructions in terms of the schedule and the food that accompanies the intake [3]. Previous studies have reported adherence rates ranging from

26–89% [11–14]. The variability in reported adherence rates depends on the operational definition of adherence and the instrument used for its measurement [15]. The pharmacological adherence is overestimated when it is calculated based on the ratio of pills forgotten and prescribed in the last days. A more precise evaluation requires the inclusion of aspects such as the follow-up of the schedule and special instructions or the last missed dose [16]. It is worth mentioning that several patterns of pharmacological nonadherence have been identified: difficulties to initiate treatment, temporary suspension (whose duration is variable), or definitive abandonment, which represents a long-term pattern [17]. Nonadherence may be due to error or forgetfulness of the medication intake, as well as the conscious decision to abandon the treatment or not follow it properly [10].

The patient not only decides whether or not to initiate HAART but also decides whether to adopt a new lifestyle. The second dimension is associated with nonpharmacological adherence, which encompasses a set of practices that promote the patient's health care. It includes practices in the areas of diet, physical activity, rest, sexual health, mental health, attendance at medical appointments and attendance to laboratory studies, and avoidance of alcohol, tobacco, or other substances. Medication intake needs to be complemented by a series of healthy practices to promote the care of the patient and the improvement of their quality of life.

Adherence can be conceived as a process that develops over time. This process is affected by the socioeconomic position of the patient in a certain context, the dominant cultural values, and his personal experience with illness. At any point of time, the patient may be adherent or nonadherent. To be adherent, the patient needs to follow both pharmacological and nonpharmacological treatment. However, there is a risk that the patient develops patterns of nonadherence (pharmacological or nonpharmacological), which occur in the short term (at a point in time) or in the medium and long terms (at multiple time points) (**Figure 1**).

Four possible scenarios can be contemplated in a single moment of the treatment: (1) The patient is adherent at the pharmacological and nonpharmacological level (ideal scenario);

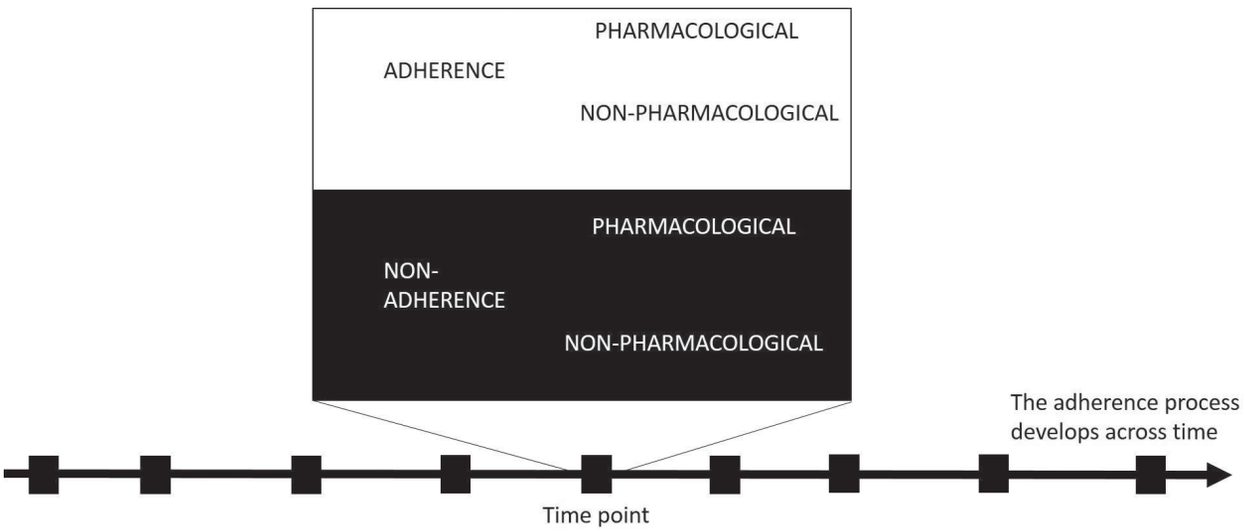

Figure 1. Adherence and nonadherence to treatment at a time point.

(2) the patient is adherent at the pharmacological level, but not at the nonpharmacological level (scenario where the patient takes the medication, but does not perform the other types of care); (3) the patient is adherent at the nonpharmacological level, but not at the pharmacological level (scenario where the patient performs healthcare practices, but does not take the medication according to the indications); and (4) the patient is not adherent in both dimensions (the worst-case scenario).

It should be mentioned that the identification of a patient as adherent will depend on the way in which the health personnel evaluate the taking of the medication and the recommendations of food and schedule (pharmacological adherence), as well as the evaluation of the degree of accomplishment of the practices in different areas of care (nonpharmacological adherence). Adherence can be considered in terms of degrees of a continuum; however, it is also necessary to establish what is the sufficient level of pharmacological and nonpharmacological adherence. This implies the need for a continuous dialog between the patient and the health personnel, in order to determine the levels of pharmacological and nonpharmacological adherence required, collaborate in the monitoring of the types of adherence, and receive feedback on the actions performed by both actors to maintain adherence.

Before reaching an optimal level of adherence, patients can alternate between periods of adherence and nonadherence until achieving an adequate and stable adherence. Traditionally it has been considered that patients are rational subjects who make a balance between the benefits and the costs of treatment to decide if they will remain adherent. However, it is necessary to consider the affective dimension, since patients not only accept treatment, they can also experience ambivalence or rejection toward treatment. It is necessary to remember that illness generates discomfort in function of the rupture it causes in the life of patients, since it affects their biography, identity, daily world, and social relations. Patients not only have the task of taking care of their health and adhering to treatment, simultaneously they embark on the tasks of giving meaning to life with the HIV infection and the reconstruction of their social world to incorporate illness in everyday life [18].

Adherence can be seen as a dialectical process where facilitators and barriers coexist during treatment. In the next section, the main facilitators and barriers to adherence reported in the literature, whether at the individual, interpersonal, or contextual levels will be reviewed.

3. Facilitators and barriers to adherence to treatment in people living with HIV

In the literature, several factors associated with adherence to treatment have been reported. A series of studies have identified the following factors based on cross-sectional studies, from the perspective of the researchers [19]:

- Factors related to personal attributes. They include the patient's clinical status, educational level, income, access to housing, and stability of the home.

- Factors related to the treatment regimen. It has been found that adherence is affected by the complexity of the regimen (depending on the number of pills or the type of indications for taking the medication), the ease of adapting the treatment to daily life, the use of devices for adherence (such as pillboxes or alarms), or side effects of treatment.
- Psychological factors. This level includes cognitive aspects such as concentration difficulties or forgetting, understanding of the role of antiretroviral treatment, or knowledge about the medical condition. Attitudes toward illness, treatment, and medications are also considered. Negative mental health factors include depression, hopelessness, anxiety or other types of psychiatric morbidity, alcohol or drug use, and coping through avoidance strategies. Positive factors include a positive attitude toward the future, long-term plans and goals, active coping, and stable mental health.
- Social factors. The relationship with the health service provider, the social support available, and the fear of revealing the diagnosis (linked to social processes of stigma and discrimination) have been identified.
- Structural factors. It includes access to treatment and health services, also economic resources to stay in treatment.

In another series of studies based on qualitative methods, facilitators and barriers to adherence have been identified from the perspective of people living with HIV. A facilitator is any individual attribute (physical, cognitive, emotional, or behavioral), characteristic of treatment, interpersonal process, or contextual aspect that favors the adherence process. In opposition, a barrier is the individual attribute, characteristic of treatment, interpersonal process, or contextual aspect that limits the adherence process.

At the individual level, beliefs that facilitate adherence have been found, such as the recognition of the drug's role in the prevention of death and illness, the perception of medicine as responsible for the improvement of health and well-being, the establishment of the maintenance of health as a priority, and religious beliefs. At an affective and motivational level, adherence is facilitated by the fear of experiencing opportunistic infections or hospitalizations, getting used to the presence of side effects, the emotional work of appropriating the suffering and feeling pride in their coping, having incentives as significant persons or future plans, adopting an optimistic perspective toward the future, or the will to live [20–25].

Other aspects that influence adherence are related to the impact of treatment, such as the absence of side effects or the clinical results of treatment. Among the practices that promote adherence are the use of external reminders, taking the medicine when the patient needs to leave the home, dealing with side effects, self-monitoring of symptoms and energy level, and conducting laboratory studies. Over time, taking the medication becomes a habit that is performed automatically [20–25].

Among the contextual aspects that facilitate adherence are having a stable lifestyle, the inclusion of treatment in the lifestyle, and the association of medication intake with daily routines. At the interpersonal level, there are facilitators such as access to positive

sources of social support and the maintenance of a collaborative relationship with health personnel [20–26].

As has happened with the facilitators, the main barriers have been identified at the individual level. Adherence is affected by beliefs about antiretroviral treatment, lack of information about treatment, beliefs about illness, as well as minimizing the risks of living with HIV. It is also affected by aspects associated with the patient's physical condition, such as forgetfulness, fatigue, or feeling sick. Even self-care can be neglected when the patient perceives a good health status. At the affective level, adherence is limited by the emotional impact of diagnosis, lack of acceptance, or rejection of treatment because it remembers the presence of HIV. Other aspects that hinder adherence are the fatigue of medication, anger, depression, despair, or other vital concerns beyond health [23–27].

The barriers to adherence associated with the patient's context are the interference of treatment with the daily routine, the changes in the routine, and the workload or being out of home during the moment of medicine intake. At the interpersonal level, adherence is limited by the lack of social support and conflicts in the relationship with health personnel [20, 22, 25]. There are also barriers linked to social inequality. Some are of an economic nature, such as the difficulty to cover the expenses required for transportation to medical appointments or to maintain an appropriate diet [23, 24]. Other barriers are related to the internalization of stigma and the fear of discrimination. There are also barriers associated with gender inequality, such as differences in access to medical services and treatment or in the negotiation of condom use, especially when the couple denies the diagnosis of HIV [28]. Men may reject adherence as a form of resistance to "body discipline" [26].

In the previous section, it was mentioned that at any time during the treatment process, the patient faces the dilemma of adhering or not adhering. Adherence involves both taking the medication according to the specified conditions and adopting a healthy lifestyle in multiple areas. It should be added that at each moment of the treatment process, the patient encounters multiple facilitators and barriers to adherence (**Figure 2**).

At the individual level, there are facilitators and barriers of different types: physical, cognitive, affective, motivational, and practical. Traditionally, health psychology has focused on modifying these elements to promote adherence. However, there are also facilitators and barriers at the interpersonal level, specifically linked to social relationships established in areas such as family, friends, health services, or the community. At this level, different types of interventions are required: family interventions, interventions focused on providing social support or expanding the patient's network, interventions focused on improving interaction with health personnel, and interventions to modify the organization of health services.

Finally, there are facilitators and barriers that are part of the patient's life context: daily routines, work and home conditions, and economic conditions. There are also conditions that can limit access and permanence in health services, such as gender inequality and social processes of stigma and discrimination. This level needs to be considered not only to adjust the treatment

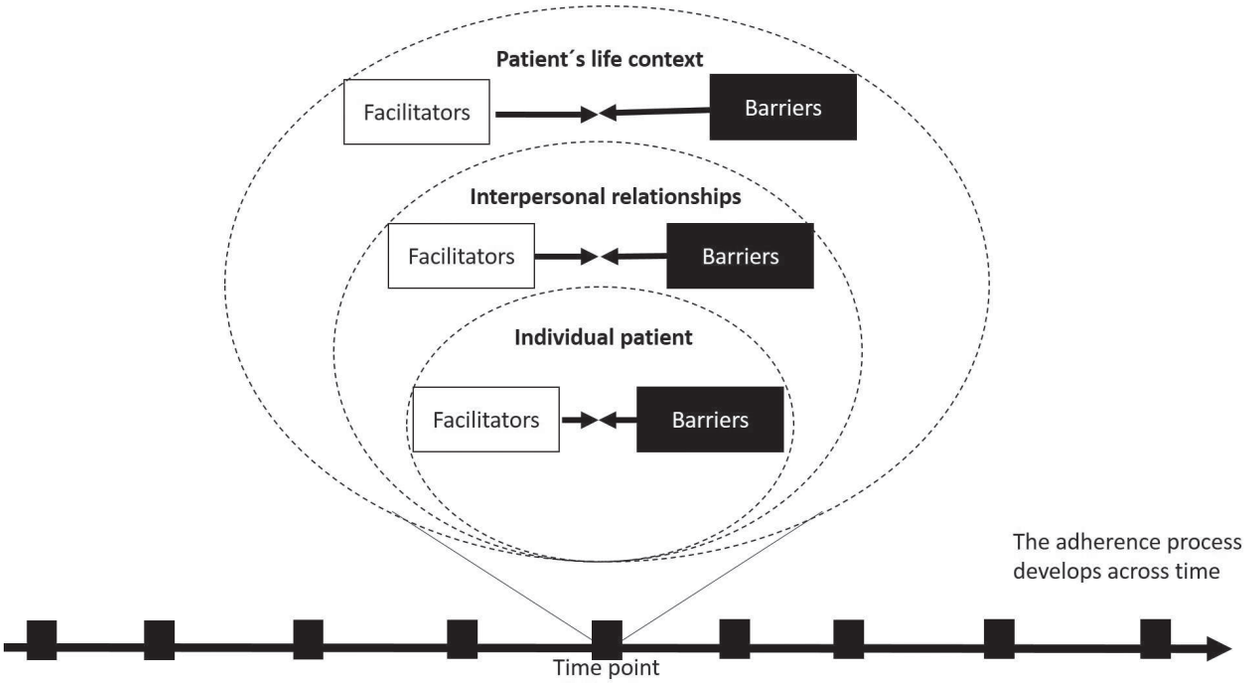

Figure 2. Facilitators and barriers to adherence to treatment, at different levels.

to the context of the patient's life but also to develop social interventions and public policies that benefit the adherence of patients in conditions of greater social vulnerability.

The identification of facilitators allows health personnel to understand the elements that contribute to the maintenance of good adherence by the patient, whether in the pharmacological or nonpharmacological dimension. The identification of barriers allows health personnel to provide feedback to the patient on those individual, interpersonal, or contextual aspects that limit the treatment and to plan the interventions required to improve the level of adherence (at the individual or collective level). It can even help in the anticipation of relapses, since both the patient and the health personnel can work collaboratively to design and implement strategies that reduce the impact of the barriers.

The following section shows how the facilitators interact to promote adherence, from the perspective of highly adherent patients. Likewise, barriers reported by these patients are identified, both for pharmacological and nonpharmacological adherence. This last type of adherence is not usually represented in adherence studies of people living with HIV.

4. Maintain adherence to antiretroviral treatment: perspective of highly adherent patients

From an individual level, the adherence process requires the interaction of different dimensions. The first dimension covers the beliefs that patients construct about illness and treatment.

Patients with high levels of adherence believe that HIV infection acts by replicating the virus within the body and decreasing the defenses, allowing the appearance of symptoms and diseases. In opposition to the beliefs about illness, they consider that HAART stops the virus and allows the defenses to increase, which strengthens the immune system. Although they recognize the benefits of pharmacological treatment, the main cost is the presence of side effects. The short-term effects are perceived as temporary and as indicators of an adaptation of the body. They mainly recognize gastrointestinal symptoms and alterations in mood or perception. Long-term effects are perceived as more damaging, due to their impact on physical appearance, metabolism, internal organs, or sensory and motor alterations [29].

Although the knowledge of common sense about illness can vary according to the cultural context of the patient, its socioeconomic position, or its level of education, it is important to point out that patients need to elaborate a basic explanatory model based on the relationship with health personnel and the education they get about their medical condition. This explanatory model establishes a common basis for collaboration with health services, since it allows to give meaning to care practices and to recognize their own vulnerability. Possibly beliefs about illness contribute to the identification of the threat and susceptibility to HIV infection, while beliefs about treatment favor the identification of the benefits in the care process. A crucial aspect is that the patient evaluates the benefits of the treatment more favorably than the costs of the side effects.

Patients also elaborate beliefs about adherence to treatment. This process is mainly associated with taking the medication, which may imply that greater importance is attached to the pharmacological adherence. This not only reflects the interests of the patient, since in the health services, there is also a greater concern for monitoring medication intake. In addition to taking the medication, patients consider that maintaining adherence requires two fundamental conditions. One of them is responsibility, because becoming a patient involves adopting the discipline of treatment.

The second condition is that patients maintain the desire to live, instead of "falling emotionally." This refers to the situation in which patients deny or reject the diagnosis, or they are depressed and put their health at risk. Therefore, in order to maintain the medication intake over time, patients need to accept the diagnosis and keep the will to live. Only in this way can patients take responsibility for their own care and incorporate the treatment discipline into their daily life, for a long period of time [29].

To stay under treatment, it is essential that patients anticipate the consequences if they do not adhere. These are the main consequences associated with nonadherence: (1) the treatment will stop working; (2) the virus is going to replicate; (3) the virus is going to become resistant; and (4) the problems will begin, such as the decrease of defenses and the emergence of diseases. It should be noted that the anticipated consequences are consistent with beliefs about illness and treatment. Another aspect that needs to be highlighted is the ability of the adherent patients to take care of themselves, even though the consequences of nonadherence are not visible (such as the replication of the virus or its mutation in resistant strains) or do not occur immediately.

The second dimension of the individual adherence process is affective. It is associated with the meaning they construct about illness, because this is an indicator of the relationship they establish with HIV infection and, in turn, the degree of acceptance of the diagnosis. From the perspective of patients, acceptance of HIV is one of the central conditions for maintaining adherence. There are different types of relationships established by highly adherent patients with their illness. Some consider that HIV infection is a motivation or challenge that drives them to get ahead, that is, a medical condition that acquires a positive meaning because it forces them to fight in life.

From a more pragmatic stance, there are patients who perceive illness as a "normal" and manageable health condition. In this case, patients normalize HIV infection in their daily lives, but they do not grant it a more transcendental meaning or consider it as a point of transformation of the self. However, they consider that they have some control over the medical condition. Finally, there are patients who conceive HIV infection as an opportunity to change toward a more moderate life. This position seems to make it easier for patients to adopt a healthier lifestyle, but at the same time, it may be linked to a desire to rebuild their social identity [29]. It seems that attributing a positive sense to illness contributes to adherence, regardless of the degree of transcendence granted in the patient's life or the impact on their identity.

In a third dimension, there are the motivational aspects that favor the adherence process. Highly adherent patients indicated three main aspects: (1) loving and taking care of themselves, (2) the family, and (3) the desire to live and "move forward" [29]. These motivational elements are not important only for the beginning of treatment but especially for its long-term maintenance. Adherence can be promoted when patients take care of themselves for the sake of their own well-being or because they want to be well for others. Possibly good adherence is an indicator of psychological well-being and positive relationships in the patient's social environment.

The fourth dimension of adherence is of a practical nature and includes the various actions or strategies that patients carry out to maintain adherence over time. For pharmacological adherence, short-term strategies were identified, such as, the use of external reminders (alarms, notes, diaries, or pillboxes), organizing the medication intake at specific moments of the daily routine, leaving the medication in special places to remember the intake, taking the medication in case of leaving home, reminder of medication intake by relatives, and not stop taking the medication if the schedule was not followed. The short-term strategies are focused on avoiding forgetfulness, which is the main barrier to pharmacological adherence even in highly adherent patients. In the long term, taking the medication is easier because it becomes a habit and is remembered mentally. There are also other strategies such as adapting to side effects and having willpower, which, unlike the previous strategies, seem to be more idiosyncratic and linked to stoicism [29, 30].

Regarding nonpharmacological adherence, patients indicated strategies according to each area of health care [29, 30]:

- Diet. Their strategies are to avoid harmful foods and try to eat healthy foods (low in fat and carbohydrates, high in vitamins and minerals).

- Physical activity. Patients establish an exercise routine or incorporate the activities of their daily routine as exercise.
- Rest. The strategies consist of sleeping 7 to 8 hours, not staying up late, and taking naps.
- Substance use. Some patients report having quit smoking or drinking (by willpower and not by specialized treatment, especially when there are low levels of previous consumption). In the case of patients who have not stopped drinking, they point out that consumption becomes occasional, only at parties or celebrations.
- Sexual health. Patients use strategies such as refusing to have sex without a condom, having condoms available, or creating justifications for condom use (such as avoiding pregnancy), especially when there is a difference in power in the couple or they are afraid of being discriminated against because of their medical condition. One facilitator of these practices is the fear of reinfection or contracting another sexually transmitted disease.
- Mental health. Patients resort to strategies such as attending psychological care (individual therapy or self-groups), obtaining social support in the family or in religious groups, and thinking positively.
- Attendance at medical appointments. Strategies were mentioned such as the use of external reminders, saving money to attend the appointment (due to transportation expenses), "keeping an eye on the appointment," or remembering it internally.
- Attendance to laboratory tests. The use of external reminders was pointed out as the only strategy. One aspect that facilitates attendance at appointments is the desire to know the health status, specifically the viral load and the level of CD4 cells.

The adherence process from the perspective of the individual patient involves the interaction between four dimensions. The first dimension comprised beliefs about illness, treatment and adherence. These beliefs require coherence with each other and with the explanatory model of health personnel. To promote adherence at this level, health education is required to provide knowledge on critical aspects of HIV infection. At the same time, it is important that a relationship be established between the patient and the health personnel where the agreement between explanatory models is verified and the dialog is facilitated for the modification of beliefs that affect the adherence process.

The second dimension is affective and focuses on the relationship that patients establish with their illness. This is an indicator of the degree of acceptance of HIV infection. Patients will not elaborate the same meaning about illness, as this depends on the psychosocial impact that HIV infection has on their lives. The impact can be diminished by coping strategies and the sources of social support they have to manage the consequences of the medical condition in daily life. It is important not to force the patient to perceive the HIV infection in a certain way; it is necessary to respect his time for acceptance. It is not necessary for the patient to perceive the diagnosis as a transcendental event that has transformed their existence or their identity, but it is a good indicator for adherence when the patient constructs a positive meaning of

illness and considers it a manageable condition. Although the meaning of illness is elaborated over time, its acceptance can be promoted through individual therapy. Especially useful are the support groups, because the construction of new discourses about living with HIV is promoted within the framework of these social relations.

The third dimension is motivational and consists of identifying those elements that encourage the patient to start treatment but, above all, maintain adherence in the long term. The main sources of motivation are individual (like the desire to continue living and taking care of oneself) and interpersonal (taking care of oneself to be well for others). Both sources are important and complement each other, but individual motivations should be emphasized, especially when patients have scarce social networks or persistent conflicts exist in their social network. Individual or group psychotherapy can strengthen individual motivation, but it is also necessary to take into account the role of social support from family members, friends, or the couple in patient care to promote interpersonal motivation. It is worth mentioning that other possible motivations that can be explored with patients are future goals or plans, since self-care is strengthened when there is a specific purpose that is to be achieved in the short, medium, or long terms.

The fourth dimension is practical and includes strategies for the two types of adherence. The strategies for pharmacological adherence are mainly focused on remembering the medication, so they can be promoted from health education, by behavioral modeling of strategies by health personnel, or through social learning in support groups. Another aspect that needs to be addressed is the management of side effects of treatment, which implies a close dialog with the health personnel for the monitoring of side effects, to assess whether the patient can benefit from medications to reduce side effects or if a change in the treatment scheme is required.

Strategies for nonpharmacological adherence can also be promoted from health education, individual counseling, or support groups. In each area of health care, it is necessary to monitor the patient's behavior to establish minimum goals and to evaluate the follow-up of health recommendations. In areas where difficulties are detected, problem-solving therapy can be used to address the barriers that limit health care and prevent relapse. In case the difficulties are maintained, it is necessary to channel the patient with specialized personnel in each area, such as nutritionists, psychotherapists specialized in addictions, or self-support groups (**Figure 3**).

Different barriers may appear through the adherence process, either individual or contextual. For pharmacological adherence, the following individual barriers have been identified: forgetfulness of medicine intake, physical discomfort, side effects, and emotional distress. It should be noted that patients' emotional distress is not only linked to their biography and personality; it is a suffering with a social origin, because it is linked to stigma and discrimination processes. As contextual barriers were mentioned, the pending tasks in the domestic or work environment that interfere with medication intake. The barriers to nonpharmacological adherence for each area of health care are the following [29, 30]:

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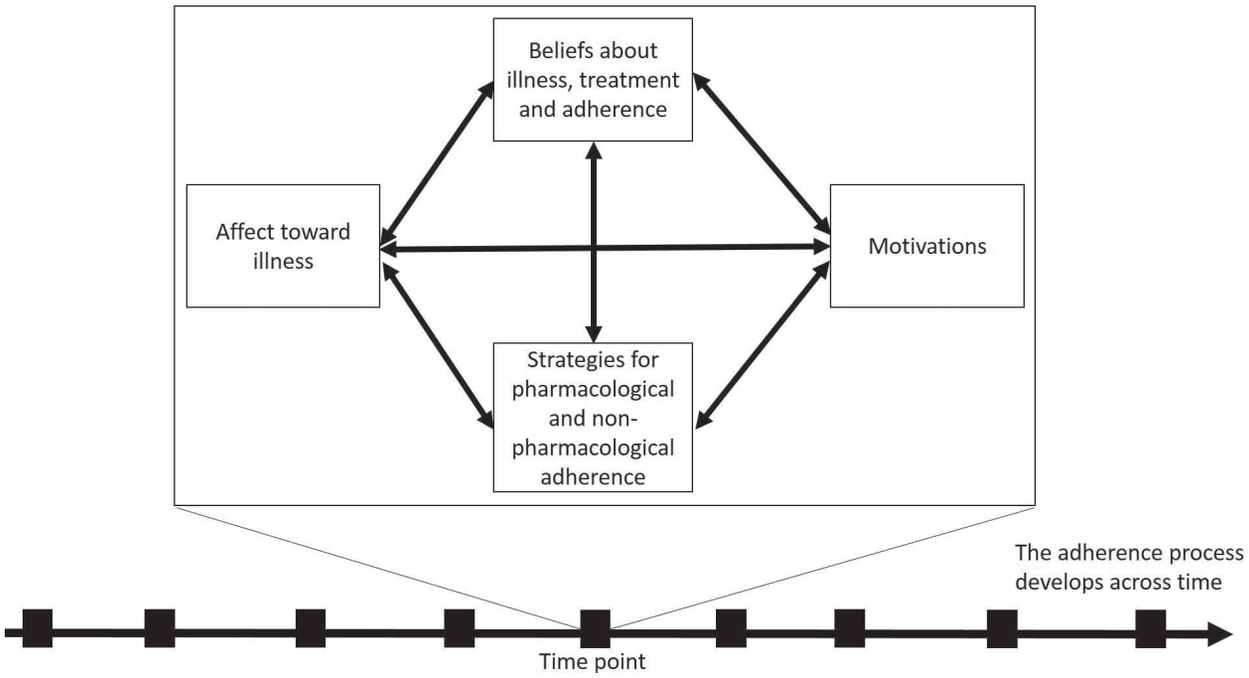

Figure 3. Dimensions of the adherence process at the individual level.

- Diet. The individual barrier is the difficulty in leaving junk food. The contextual barrier is the economic difficulty to buy healthy foods.
- Physical activity. The main individual barrier is feeling weak or tired. The contextual barrier is the lack of time to exercise.
- Rest. The most frequently mentioned individual barrier was physical discomfort. The main contextual barrier was the work schedule.
- Substance use. The individual barriers identified were tobacco addiction and not attending specialized help to quit smoking. The contextual barriers identified were friendships that consume substances.
- Sexual health. The barriers were identified in the context of the couple relationship. Some mentioned that at certain times they did not use the condom because they did not care about risk. Also mentioned was the avoidance of sexual relations with a stable partner due to the fear of transmitting HIV.
- Mental health. Depression and stigma were the main barriers to mental health. A situation mentioned by some patients was the rejection of psychological services or the desire to get ahead by themselves.
- Attendance at medical appointments. The individual barriers were forgetfulness and physical discomfort. The main contextual barriers were work and not having money for transportation.

- Attendance to laboratory tests. The barrier identified was forgetfulness. It should be mentioned that laboratory studies are performed less frequently than medical appointments.

Diet is affected not only by the habits developed in the past by the patient but also by the influence of culture on food preferences, the supply of healthy food in its sociocultural context, and feeding practices in the family. It is therefore essential that overweight and obese patients can attend a nutritional consultation to continuously monitor their weight and develop a meal plan that fits their daily routine and economic capacity.

Physical activity and rest are two areas of health care closely linked to the work context and the demands of home. The overload of daily tasks can reduce the time available for rest and exercise. If the patient cannot access a job with better conditions for their health, it is important to focus on the organization of time to get more rest hours and design a physical activity plan that adapts to the patient's daily routine and can be performed in a short time.

Substance use is an area that requires greater attention in health services. Tobacco addiction is usually minimized, and specialized care services are not frequently visited for treatment. The consumption of alcohol can be difficult to avoid in a sociocultural context where it is promoted as a ritual of socialization, which is why in health services a compromise solution is usually established: allow the patient to consume alcohol occasionally during special situations. However, health services need to send a clear message to patients regarding substance use during treatment. It is necessary for health personnel to identify the level of substance use in the patient, clearly communicate the consequences of consumption for their health and the treatment process, and conduct referral to specialized services in addiction care when required.

In the area of sexual health, adherent patients usually adopt condom use in a systematic way. However, the problems can be due to a tiredness of the use of the condom, because they perceive it as a routine act, which affects spontaneity and eroticism. These situations are not usually reported to health personnel, so it is necessary to establish a trust relationship with the patient so that they can talk about these issues and request help when necessary. In the care services, interventions that address the eroticization of condom use can be implemented.

Especially, it is necessary to be alert when patients are immersed in power relations where the negotiation of condom use is limited. On the other hand, some patients report that they have stopped having sex for fear of transmitting HIV. In these cases, it may be necessary to provide relevant information about transmission risks and protected sex practices. Counseling sessions for the couple can also be developed to clarify doubts about the transmission of HIV and provide alternatives for safe sex and protected sex.

The mental health of patients can be compromised from the moment of diagnosis, because it generates emotional distress and limits the acceptance of HIV. This is due not only to a patient's vulnerability in psychological terms but also because of the social vulnerability associated with their socioeconomic position and the processes of stigma and discrimination. Psychological care (at the individual or group level) is essential before starting treatment so

that the patient can accept the illness and emotionally prepare to maintain adherence. A problem is that in health services, care is not usually promoted in an integral way, but mainly physical health care is considered and mental health is not sufficiently attended. Another difficulty lies in the rejection of patients to psychological care, either because of the stigma toward mental illness or the desire to solve their psychosocial problems individually.

Finally, attendance at medical appointments or laboratory tests is often affected by forgetfulness. Reminders via telephone, text message, or social networks can be useful to promote adherence in this area. Some patients pointed to work as a barrier, which can be reduced if health centers establish a policy for extending the schedules of service. Physical discomfort can be a barrier when a health problem makes it difficult to attend the health center, so they can benefit from special procedures for changing appointments in such circumstances. Certain patients' report has economic difficulties for transport payment. In certain vulnerable groups, financial support may be granted for attendance at medical appointments (**Figure 4**).

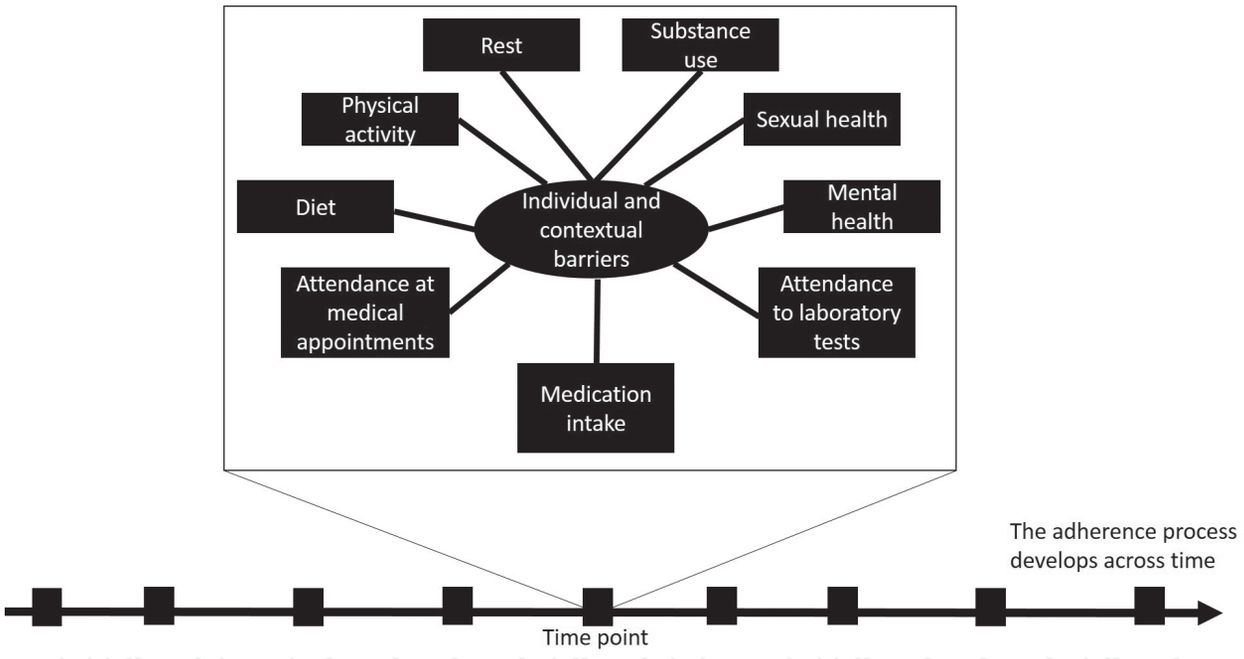

Figure 4. Individual and contextual barriers during the adherence process.

5. Conclusions

Adherence is a process that develops over time, where people living with HIV need to identify as patients, take an active role in their health care, and establish a collaborative relationship with health personnel. The agency capacity is not the same for all patients; it depends on their level of social vulnerability. This means that there are structural conditions that reduce the capacity of agency and the options of patients in their daily lives. Patients are not only rational subjects who make decisions regarding treatment based on a cost–benefit analysis;

they are at the same time affective subjects who need to deal with the rupture of their social world caused by a medical condition that is stigmatized in his cultural context.

Adherence has two dimensions: pharmacological and nonpharmacological. At any time in the adherence process, patients may become nonadherent, in one or both dimensions. The patterns of nonadherence can be generated in the short, medium, and long terms; persistent patterns that extend over time are more problematic. From the perspective of the individual patient, adherence is maintained at any point of time due to the interaction of the following elements: beliefs about illness, treatment and adherence, affection toward HIV infection, motivations, and strategies for taking medication and health care. However, the patient may encounter individual and contextual barriers in multiple areas: medication intake, diet, rest, physical activity, substance use, sexual health, mental health, attendance at medical appointments, and attendance to laboratory tests. Health services require a comprehensive evaluation of the patient in each of the areas indicated, in order to understand the resources available to the patient for adherence and the barriers that require specific interventions.

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